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Health-related quality of life in young adult patients with rheumatoid arthritis in Iran: reliability and validity of the Persian translation of the PedsQL™ 4.0 Generic Core Scales Young Adult Version

Pakpour, Amir H ; Zeidi, Isa Mohammadi ; Hashemi, Fariba ; Saffari, Mohsen ; Burri, Andrea

Abstract: The objective of the present study was to determine the reliability and validity of the Persian translation of the Pediatric Quality of Life Inventory (PedsQL™) 4.0 Generic Core Scales Young Adult Version in an Iranian sample of young adult patients with rheumatoid arthritis (RA). One hundred ninety-seven young adult patients with RA completed the 23-item PedsQL™ and the 36-item Short-Form Health Survey (SF-36). Disease activity based on Disease Activity Score 28 was also measured. Internal consistency and test-retest reliability, as well as construct, discriminant, and convergent validity, were tested. Confirmatory factor analysis (CFA) was used to verify the original factor structure of the PedsQL™. Also, responsiveness to change in PedsQL™ scores over time was assessed. Cronbach's alpha coefficients ranged from $\alpha = 0.82$ to $\alpha = 0.91$. Test-retest reproducibility was satisfactory for all scales and the total scale score. The PedsQL proved good convergent validity with the SF-36. The PedsQL distinguished well between young adult patients and healthy young adults and also RA groups with different comorbidities. The CFA did not confirm the original four-factor model, instead, analyses revealed a best-fitting five-factor model for the PedsQL™ Young Adult Version. Repeated measures analysis of variance indicated that the PedsQL scale scores for young adults increased significantly over time. The Persian translation of the PedsQL™ 4.0 Generic Core Scales Young Adult Version demonstrated good psychometric properties in young adult patients with RA and can be recommended for the use in RA research in Iran.

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Health-Related Quality of life in Young Adult Patients with Rheumatoid Arthritis in Iran: Reliability and Validity of the Persian Translation of the PedsQL™ 4.0 Generic Core Scales Young Adult Version

Amir H Pakpour *^{1, 2}, Isa Mohammadi Zeidi¹, Fariba Hashemi¹, Mohsen Saffari³

Andrea Burri^{4,5}

¹ Qazvin Research Center for Social Determinants of Health, Qazvin University of Medical Sciences, Qazvin, Iran

² Department of Public Health, Qazvin University of Medical Sciences, Qazvin, Iran

³ Department of Health Education, Baqiyatallah University of Medical Sciences, Tehran, Iran

⁴ Department of Twin Research and Genetic Epidemiology, King's College London

⁵ University of Zurich, Department of Psychology, Psychopathology and Clinical Intervention, Switzerland.

Running Head: rheumatoid arthritis and quality of life in young adults

Address correspondence to: Amir H Pakpour, PhD, Assistant professor, Department of Public Health, Qazvin University of Medical Sciences, Qazvin, Iran.

Phone: +98-281-3338127

Fax: +98-281-3345862

Email: Pakpour_Amir@yahoo.com

Abstract

The objective of the present study was to determine the reliability and validity of the Persian translation of the PedsQL™ 4.0 Generic Core Scales Young Adult Version in an Iranian sample of young adult patients with rheumatoid arthritis (RA). 197 young adult patients with RA completed the 23-item PedsQL™ and the 36-item SF-36 Health Survey. Disease activity based on Disease Activity Score 28 (DAS28) was also measured. Internal consistency and test–retest reliability, as well as construct, discriminant and convergent validity were tested. Confirmatory factor analysis (CFA) was used to verify the original factor structure of the PedsQL™. Also, responsiveness to change in PedsQL™ scores over time was assessed. Cronbach’s alpha coefficients ranged from $\alpha=0.82$ to $\alpha=0.91$. Test-retest reproducibility was satisfactory for all scales and the total scale score. The PedsQL proved good convergent validity with the SF-36. The PedsQL distinguished well between young adult patients and healthy young adults and also RA groups with different comorbidities. The CFA did not confirm the original four-factor model, instead analyses revealed a best-fitting five-factor model for the PedsQL™ Young Adult Version. Repeated-measures analysis of variance indicated that the PedsQL scale scores for young adults increased significantly over time. The Persian translation of the PedsQL™ 4.0 Generic Core Scales Young Adult Version demonstrated good psychometric properties in young adult patients with RA and can be recommended for the use in RA research in Iran.

Keywords: PedsQL, quality of life, rheumatoid arthritis, young adults, patient reported outcomes, Iran, psychometric validation

Introduction

Rheumatoid arthritis (RA) is a chronic autoimmune disease that leads to inflammation of the joints and surrounding tissues [1]. RA may also affect other organs such as heart, liver, and etc. The etiology of RA remains unknown [1-2].

The fatigue, pain, stiffness and joint swelling as a result of RA is recognized as a significant cause of patients' functional disability [3]. It was estimated that RA affects 1% of the adult American population [4]. In Europe, the incidence rate of RA varies between a low 8.8/100000 for France to a high 24-36/100000 incidence for Scandinavian countries [5-6]. A recent study in Iran revealed a prevalence of RA of 0.19% and 0.33% for rural and urban areas, respectively [7-8]. The prevalence of the RA increases with age, and there is higher incidence in women compared with men [9]. Although the burden of RA is substantial for pediatric and adults patients [9], RA has been shown to have greater effects on patient's activities, mental health and pain in younger patients [10]. Chronic diseases, such as RA, in youth are associated with high pain, disability, depression, impaired work and school functioning [10, 12-14]. Furthermore, being a young adult with RA predicts future disability, pain, and well being in adulthood [11]. There is a general agreement among health care professionals that considering symptoms of RA alone as medical outcomes are not sufficient. The concept of quality of life has been increasingly used not only for assessing daily clinical practice but has recently also been recognized as an important disease and health related outcome measure [15-16]. Health related quality of life (HRQOL) is defined by the World Health Organization (WHO) as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, and standards and concerns" [17]. HRQOL is a multidimensional concept which encompasses physical

health, psychological state, level of independence, social relationships, and people's relationships to salient features of their environment [17]. Assessment of HRQOL helps following the trends of improvements, the assessment of treatment effects, and the identification of strategies to prevent adverse complications in RA patients [18]. Several generic HRQOL assessment instrument exist, such as the Medical Outcomes Study 36- Item Short-Form Health Survey (MOS SF-36) [19]. Disease-specific measures to assess HRQOL among patients with RA include the Stanford Health Assessment Questionnaire (HAQ) [20-21] and the Arthritis Impact Measurement Scales (AIMS) [22]. While disease specific measures cover all the specific factors of RA (i.e. clinical features of RA), generic measures have the ability to compare health status in any population regardless of the disease or condition [23-24]. Although, the SF-36 has been widely used to assess HRQOL in patients with RA [24], it does not fully consider all aspects of the patient's quality of life. A recent study revealed that limited activity at school and work place were major complains of adolescent patients suffering from RA [25]. The Pediatric Quality of Life Inventory (PedsQLTM) was originally developed by Varni et al and used to assess health conditions in pediatrics with chronic disease [26]. In contrast to the SF-36, the PedsQL includes school/work functioning as an important aspect of patients' life. The PedsQL was originally used in children aged 2 to 18 years and their parents. The PedsQL has been widely used for various diseases with acceptable measurement properties. Recently, efforts have been made to provide continuity of in assessing HRQOL assessment in young patients after the age of 18 [27] with the PedsQLTM 4.0 Generic Core Scales Young Adult Version was administrated in a U.S university student population (aged 18 to 25) [27] and validation analyses confirmed a high internal consistency and could successfully differentiate between healthy people and youth with chronic diseases [27].

To the best of our knowledge, there is no study that assesses HRQOL in young adult patients with RA in Iran. The aim of this study was therefore to cross-culturally adapt the PedsQL and to assess HRQOL in Persian-speaking RA patients.

Methods

Participants

From February 2010 to April 2011, n=197 patients with RA who had been referred to from the rheumatology clinic at the Boo-Ali hospital were recruited. An expert rheumatologist confirmed the diagnosis of RA according to the criteria set by the American College of Rheumatology [28]. Criteria for study inclusion were: age from 18 to 25; a confirmed diagnosis of RA by a rheumatologist; willingness to participate in the study; fluency in written and spoken Persian. The study protocol was approved by the research ethics committee of the Qazvin University of Medical Sciences. All participants gave their written informed consent.

Measurements

A demographic questionnaire was designed to collect information on basic demographic factors such as age, gender and educational status. Furthermore, clinical variables including duration of RA, number of tender and swollen joint, and erythrocyte sedimentation rate (ESR) were also evaluated.

Disease Activity Score-28 (DAS28)

Disease activity was measured by the DAS28 [29]. The DAS28 is a useful measure to evaluate inflammatory disease activity in RA and includes four parts: 1) number of tender joints 2) number of swollen joints 3) Erythrocyte Sedimentation Rate (ESR) in

blood and 4) general health assessment using a visual analogue scale (VAS). VAS (0-100) is a simple tool to evaluate pain severity as reported by patients. The DAS28 total score can be generated by using the following formula: $=0.56*\sqrt{\text{(tender joints)}} + 0.28*\sqrt{\text{(swollen joints)}} + 0.70*\text{Ln(ESR/CRP)} + 0.014*\text{VAS}$.

The SF-36

The SF-36 is a general questionnaire used to assess HRQOL [19]. It has been used successfully in chronic diseases including RA [30-31]. It includes 36 items and covers eight subscales including physical functioning (PF), role limitations due to physical health (RP), bodily pain (BP), general health perception (GH), social functioning (SF), role limitations due to emotional problems (RE), vitality (VT), and mental health (MH) [19]. The SF-36 has been translated into various languages and is also available in Persian. Measurement properties of the Persian version were previously confirmed in a population study comprising 4163 healthy Iranian adults over 15 years old [32].

The PedsQL™ 4.0 Generic Core Scales Young Adult Version

The PedsQL™ 4.0 Generic Core Scales Young Adult Version has 23 items with four subscales including: Physical Functioning (eight items); Emotional Functioning (five items); Social Functioning (five items); and Work/School Functioning (five items) [27]. These items are similar to those in the PedsQL™ 4.0 Generic Core Scales Adolescent Version (i.e. 13-18 years old) [33]. All items of the PedsQL™ 4.0 Generic Core Scales Young Adult Version score on a five-point Likert scale, ranging from “never” (0) to “almost always” (4). The scores are linearly transformed on a scale from 0 (worst condition) to 100 (best condition) [27, 33]. Besides the four

subscales, the PedsQL™ 4.0 Generic Core Scales Young Adult Version has two summary scores: the physical health summary score (8 items) and the psychosocial health summary score (15 items). To create the summary scores, the mean is computed as the sum of the specific scale-items divided by the number of items.

Procedure

The patients completed the set of questionnaires at baseline after agreeing to participate in the study. Demographic and clinical data were collected at the same time. Two weeks later, the patients were asked again to complete the PedsQL™ 4.0 Generic Core Scales Young Adult Version to ensure reliability of the instrument. However, nine patients did not complete the questionnaire dropped out and did not complete the questionnaire for the second time.

Translation

After receiving permission from the MAPI research trust, the PedsQL™ 4.0 Generic Core Scales Young Adult Version was translated into Persian by two local English-Persian bilingual translators (Forward Translation). Next, the translators discussed their translations to achieve a reconciled version.

Then, the first reconciled forward version was back translated into the source language (i.e. English) by a native English speaking, translator. The translator was not aware of the original version and had no access to the original English questionnaire version. The back-translated version was sent to the developer for review and comment. In the next step, the backward translated version of the PedsQL™ was

compared with the original English version was made and necessary modifications were made.

This second version of the translated PedsQL™ was piloted in a sample of N=11 patients with RA. A cognitive interviewing methodology with respondent debriefing technique was used for this step. Afterwards, the PedsQL™ 4.0 Generic Core Scales Young Adult Version was revised based on the results of the cognitive interviews. In the end, the resulting final version of the translated PedsQL™ 4.0 Generic Core Scales Young Adult Version was administrated to a sample of n=197 patients with RA (field testing).

Data analysis

Data were analyzed using SPSS version 16 and LISREL version 8.80.

Ceiling effects (i.e. the percentage of scores at the maximum possible scores) and floor effects (i.e. the percentage of scores at the minimum possible scores) were computed to assess the range of measurement. Floor and ceiling effects were regarded as being present if more than 15% of the responders reported highest or lowest possible scores [34].

Reliability was assessed in two ways; 1) internal consistency; internal consistency was evaluated by calculation of Cronbach's alpha Coefficient on the four subscales and total scores. A Cronbach's alpha 0.70 or higher indicates acceptable internal consistency [35]. 2) test-retest reliability was evaluated by calculating intra-class correlation coefficients (ICCs) for the 2 week interval. ICCs ≤ 0.40 , 0.41-0.59, and ≥ 0.60 are considered small, medium and large, respectively [36].

Convergent validity was examined by computing intercorrelations between the PedsQL™ subscales and the SF-36 subscales. It was assumed that the PedsQL™ correlated positively with the SF-36.

Known group comparison was used to assess discriminant validity of the PedsQL 4.0 Generic Core Scales young adult version. N=1803 healthy young people were randomly selected from Qazvin University of Medical Sciences with similar age and sex distribution. Based on previous studies it was assumed that healthy people reported higher scores than people with RA [37-39]. According to the previous studies, HRQOL are affected by comorbidities [40-41]. Thus, patients with at least one medical comorbidity were compared with those patients reporting no comorbidities based on quality of life scores.

The factor structure of the PedsQL 4.0 Generic Core Scales young adult version was evaluated using confirmatory factor analysis (CFA). CFA was applied to for both groups (i.e. patients with RA and healthy young adults) to verify the original four-factor structure [27, 33]. A weighted least squares (WLS) estimation method was used to perform the CFA. The goodness- of-fit of the model was evaluated with the following parameters: chi square (χ^2) - an absolute fit indices that is sensitive to sample size, the goodness of- fit index (GFI) , the comparative fit index (CFI) , non-normed fit index (NNFI), Parsimony Normed Fit Index (PNFI) and Root Mean Square Error of Approximation (RMSEA) . GFI, NNFI and CFI ranged from 0 to 1 and values equal or greater than 0.90 is considered acceptable fit. A RMSEA value less than or equal to .05 is considered acceptable. PNFI is considered as parsimonious fit index and ranged from 0 to 1 with higher values indicating a more parsimonious fit [42]. In the study, two models were tested; a four-factor model for healthy young adults (n=1803) and a hypothesized four-factor model for patients with RA (n= 197).

Despite of the existing scale structure of the PedsQL (i.e. four factor structure), the EFA in the original study revealed an empirical five-factor structure [43]. Therefore, a five-factor model was specified for the CFA analyses in the current study if the 4-factor structure did not yield a good fit.

To examine the ability of the PedsQL 4.0 Generic Core Scales young adult version to detect a treatment effect, the measure was administrated to a subsample of 49 patients with newly diagnosed RA. The patients were prescribed either disease modifying antirheumatic drugs (DMARDs) or nonsteroidal anti-inflammatory drugs (NSAIDs). Studies have indicated that NSAIDs can reduce pain, inflammation and stiffness in patients with RA [44-46]. On the other hands, the use of DMARDs has been shown to be effective in preventing erosive disease [46]. The patients were asked to complete the PedsQL at three different time points (baseline, three months and six months follow-up). Previous studies have recommended the use of effect size statistics for repeated measure designs [47]. However, effect sizes tend to be over-estimate if the distribution of the baseline scores is narrow. One way to avoid this problem is to use the standardized response mean (SRM). In this study SRM were computed to assess changes in the PedsQL over time (responsiveness) [48]. The SRM is obtained by dividing the mean change from baseline on standard deviation change. Values of 0.20, 0.50, and 0.80 or greater were considered to represent small, moderate, and large degrees of responsiveness, respectively. The repeated measure analysis of variance was used to test the differences between values of the three measurements. Statistical significance level for analyses was considered to be at $p < 0.05$.

Results

Demographic and clinical features of the patients are shown in table 1. The majority of the patients were female (%79). The mean age and disease duration were 23.2 months and 54.3 months, respectively. Minimal floor or ceiling effects were observed in all four subscales of the PedsQL.

The internal consistency of the Iranian version of the PedsQL was acceptable, with Cronbach's alphas ranging from 0.82 to 0.91 (Table 2).

Test-retest reliability was good, with a high intra-class correlation coefficient for the two time points (Table 2).

There were significant correlations ($P < 0.01$) between the PedsQL scores and SF-36 subscales (Table 3). A high correlation was observed between the PedsQL physical functioning scale and SF-36 physical functioning scale ($r = 0.75$).

Results of the discriminant analysis are summarized in Table 4. Healthy subjects had a significantly lower burden of disease compared with patients with RA even when considering adjusted-p values (i.e. Benjamini-Hochberg procedure). Furthermore, statistically significant differences were found in the means of the PedsQL subscales scores depending on comorbidity (Table 3). Patients with at least one comorbidity reported lower HRQOL compared with those without any comorbidity ($P < 0.001$).

The hypothesized four-factor structure was tested by the CFA for patient and healthy participant samples. The results revealed that the four-factor model did not provide an adequate fit for both patient groups ($\chi^2 = 802.94$, degree of freedom = 224, P value < 0.0001 , GFI = 0.73, NNFI = 0.89, PNFI = 0.77, CFI = 0.90 and RMSEA = 0.117) and the healthy young adult group ($\chi^2 = 556.11$, degree of freedom = 224, P value < 0.0001 , GFI = 0.78, NNFI = 0.89, PNFI = 0.76, CFI = 0.91 and RMSEA = 0.091). Therefore, an empirical five-factor structure as suggested by Varni et al was tested in which the 5-item school functioning scale splits into 3 cognitive functioning

items and 2 missed school days items [43]. In contrast to the four-factor model, for all groups the model fit and comparative indices were highest for the original 5-factor model ($\chi^2=462.48$, degree of freedom=220, P value<0.0001, GFI = 0.92, NNFI = 0.94, PNFI= 0.79, CFI = 0.94 and RMSEA = 0.076 for the patient group and $\chi^2=496.23$, degree of freedom=220, P value<0.0001, GFI = 0.91, NNFI = 0.92, PNFI= 0.79, CFI = 0.93 and RMSEA = 0.079 for the healthy young adult group).

The results regarding the changes in the PedsQL subscale scores over time are summarized in Table 5. Repeated-measures analysis of variance revealed that the mean number of the PedsQL increased significantly after the 3 months and the 6 months follow-up compared to the initial, baseline visit (Table 5). The most responsive subscale was work functioning with an SRM of 0.57 at 3 months and social functioning with a SRM of 0.70 at 6 months. Positive SRMs represent an improvement in quality of life over time. Generally the SRMs were small to moderate at 6 months follow-up, implying improvement of HRQoL occurring between 3 and 6 months (Table 5).

Discussion

The aim of this study was to assess the psychometric properties of an Iranian version of the PedsQL a sample of young adult patients suffering from RA. The Iranian version of the PedsQL showed a high internal consistency, good test–retest reliability, as well as high construct, convergent, and discriminant validity. Furthermore, the factor structure and the questionnaires responsiveness to change over time were assessed in the study.

Response variability within the population was supported by the lack of floor and ceiling effects. Therefore, the instrument can be used to detect health changes over

time. The original version of the PedsQL reported similar findings for U.S university students with chronic health conditions [27].

High Cronbach's alpha coefficients for the four domains of the PedsQL confirmed that these domains were internally consistent. The results were in line with previous findings in the original validation study in the US ($\alpha = 0.71$ to 0.86).

Reproducibility of the young adult version of the PedsQL was assessed using ICC over two weeks. All ICCs were above 0.70 therefore demonstrating high reliability/reproducibility of the questionnaire results over time. This is the first study to assess the reproducibility of the PedsQL™ 4.0 Generic Core Scales Young Adult Version. However, the stability of the PedsQL™ has been reported for different age versions [49- 51].

The study indicated that the PedsQL™ correlated moderately with the SF-36 and the VAS. As anticipated, the physical domains of the PedsQL™ correlated moderately to high with the corresponding domains of the SF-36, demonstrating that the PedsQL™ and the SF-36 capture similar conceptual areas. Again, these findings are consistent with results obtained from the initial validation study conducted on a US university sample [27].

In the present study, the PedsQL™ was able to discriminate between patients with RA and a age and gender matched, healthy university sample. Significantly higher scores on the PedsQL™ could be observed for the healthy sample compared to the RA patient sample.

Comorbidities can affect patient's functional ability [41]. A recent study demonstrated that an increasing level of functional disability is significantly associated with poorer quality of life in patients with RA [40]. However, in contrast to our study, mental functioning was not affected by comorbidity among Australian patients with RA as

shown by an earlier epidemiologic study [40]. Using different instruments to assess HRQOL and using an older sample may be potential reasons for these discrepancies in findings.

Contrary to the hypothesized four-factor structure, the CFA indicated a best fitting five-factor model of the 23 questionnaire items. There are discrepancies in the literature regarding the structure of the PedsQL™. Whilst a four-factor structure was reported in a previous study on Iranian children and adolescents with attention deficit/hyperactivity disorder [50], the Iranian version of PedsQL Generic Core Scales in adolescents supported a five-factor model, similar to the original version of the PedsQL [49]. Possible explanations for these divergent findings could be differences in demographic characteristics of the study populations, such as age, or differences in clinical variables.

The PedsQL Generic Core Scales was sensitive to change after intervention over a 3 and 6 month follow-up. At the six month follow-up, all subscales of the PedsQL showed significantly lower scores, indicating a significant improvement from baseline (all $P < 0.001$). Our results were in accordance with other studies [i.e. 44-46, 52-54].

This study has some limitations. First of all, our patients are not representative of all Iranian patients with RA. Therefore, the generalizability of this study may be limited. Thus, data should be interpreted with caution.

In conclusion, the Iranian version of the PedsQL™ has good psychometric properties and can be recommended for the use in RA research in Iran.

Disclosures

None

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Table 1. Demographic characteristics of the rheumatoid arthritis patients

	N (%)
Age (mean±SD)	23.25 (4.98)
Gender	
Male	41 (20.81%)
Female	156 (79%)
Patient's education (year; mean.SD)	8.18(3.62)
Duration of disease (month; mean.SD)	54.3 (5.46)
Number of swollen joints (mean.SD)	2.29 (1.68)
Number of tender joints (mean.SD)	4.13 (3.01)
Body Mass Index (BMI)	26.71(4.01)
DAS-28	3.83 (1.76)
VAS (0-100 mm)	42.31(19.62)
ESR (mm/h)	29.95(17.86)
Number of comorbidities	1.23 (0.86)

Table 2 Means, standard deviations, percent floor and ceiling effects, and Cronbach's Alpha for the Iranian version of PedsQL™ 4.0 Generic Core Scales Young Adult Version

Scale	Number of Items	Mean	SD	Percent Floor (%)	Percent Ceiling (%)	Cronbach's α	ICC (95% CI)
Total Score		64.33	30.96	6.09	0	0.911	0.801 (0.734-0.926)
Physical Functioning	8	66.15	34.68	3.6	4.2	0.822	0.907(0.803-0.973)
Emotional Functioning	5	63.26	28.00	4.2	1.1	0.818	0.828(0.763-0.897)
Social Functioning	5	68.92	29.19	5.1	3.7	0.826	0.776(0.635-0.864)
Work/School	5	61.97	34.57	9.5	0	0.843	0.864(0.728-0.923)

Functioning							
Psychosocial health	15	65.89	26.42	5.8	0	0.897	0.802(0.701-0.831)

Note; All p values for the ICCs are significant at $P < 0.05$
 ICC = Intraclass correlation coefficients

Table 3. Intercorrelations among PedsQL™ 4.0 Generic Core Scales Young Adult Version, VAS and SF-36 subscales

Scale	TS	PH	EF	SF	WF	PF	RP	BP	GH	VT	SF	RE	MH	PsyH	VAS
TS	-	0.77	0.77	0.84	0.84	0.50	0.46	0.32	0.32	0.36	0.44	0.39	0.56	0.68	-0.658
PH		-	0.86	0.75	0.81	0.75	0.68	0.53	0.41	0.31	0.46	0.37	0.50	0.53	-0.824
EF			-	0.89	0.86	0.42	0.48	0.43	0.47	0.52	0.58	0.55	0.59	0.66	-0.629
SF				-	0.89	0.47	0.41	0.57	0.58	0.59	0.41	0.58	0.51	0.69	-0.803
WF					-	0.44	0.38	0.49	0.51	0.24	0.30	0.42	0.47	0.68	-0.863
PF						-	0.69	0.56	0.51	0.74	0.53	0.47	0.58	0.47	-0.706
RP							-	0.71	0.64	0.49	0.53	0.56	0.42	0.51	-0.552
BP								-	0.52	0.48	0.45	0.58	0.52	0.54	-0.520
GH									-	0.81	0.72	0.63	0.54	0.62	-0.769
VT										-	0.59	0.68	0.56	0.60	-0.618
SF											-	0.58	0.70	0.68	-0.709
RE												-	0.79	0.65	-0.647
MH													-	0.71	-0.803
PsyH														-	-0.710
VAS															-

TS =Total Generic Core Scales; PH= Physical Health Summary Score; EF= Emotional Functioning Scale; SF = Social Functioning Scale; WF= Work Functioning Scale; PsyH= Psychosocial health.

All *P<0.05

Table 4. Comparison of the PedsQL™ 4.0 Generic Core Scales Young Adult Version for condition categories and comorbidities

Scale	Health status		Comorbidity	
	rheumatoid arthritis (n=197)	Healthy university sample (n=1803)	0 (n=125)	≥1 (n= 72)
Total Score †‡	64.33 (30.96)	76.42 (15.85)	65.63(14.51)	58.69(17.42)
Physical Functioning†‡	66.15 (34.68)	77.67(18.10)	69.07(15.17)	59.65(2185)
Emotional Functioning†‡	63.26 (28.00)	80.28(21.92)	66.86(21.76)	54.72(21.67)
Social Functioning†‡	68.92 (29.19)	83.83(10.02)	70.82(17.40)	62.51(19.45)
Work/School Functioning†‡	61.97 (34.57)	73.54(20.46)	62.75(18.86)	56.87(22.98)
Psychosocial health†‡	63.04 (28.46)	76.81(29.74)	59.24(17.81)	66.76(26.68)

† Statistically significant according to Benjamini-Hochberg procedure for Health condition

‡ Statistically significant according to Benjamini-Hochberg procedure for number of comorbidities

Table 5. Responsiveness of the PedsQL™ 4.0 Generic Core Scales Young Adult Version for newly diagnosed patients with rheumatoid arthritis (n=49; 17 men, 32 women).

	Baseline	First follow-up	Second follow-up	SRM 0-3 months	SRM 3-6 months	P ^a
	Mean(SD)	Mean(SD)	Mean(SD)			
Total Score	54.37(15.64)	60.24(15.25)	69.01(14.61)	0.39	0.59	0.006
Physical Functioning	50.54(20.46)	63.03(26.18)	75.51(22.77)	0.55	0.51	0.007
Emotional Functioning	51.42(21.48)	56.88(19.34)	67.03(22.92)	0.27	0.51	0.009
Social Functioning	54.67(18.10)	60.17(17.19)	71.43(15.99)	0.30	0.67	0.002
Work/School Functioning	60.83(18.02)	71.18(19.48)	80.59(20.97)	0.57	0.48	0.001
Psychosocial health	54.26(16.65)	61.70(16.39)	72.69(16.01)	0.46	0.70	0.008

a: repeated measure analysis of variance, SRM: Standardized Response Mean

Appendix A

PedsQL™ 4.0 Generic Core Scales Young Adult Version Items

Physical Functioning Scale

1. It is hard for me to walk more than one block
2. It is hard for me to run
3. It is hard for me to do sports activity or exercise
4. It is hard for me to lift something heavy
5. It is hard for me to take a bath or shower by myself
6. It is hard for me to do chores around the house
7. I hurt or ache
8. I have low energy

Emotional Functioning Scale

1. I feel afraid or scared
2. I feel sad or blue
3. I feel angry
4. I have trouble sleeping
5. I worry about what will happen to me

Social Functioning Scale

1. I have trouble getting along with other young adults
2. Other young adults do not want to be my friend
3. Other young adults tease me
4. I cannot do things that others my age can do
5. It is hard to keep up with my peers

Work/School Functioning Scale

1. It is hard to pay attention at work or school
2. I forget things
3. I have trouble keeping up with my work or studies
4. I miss work or school because of not feeling well
5. I miss work or school to go to the doctor or Hospital

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